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The social construction of remission for people with a diagnosis of schizophrenia

Accessible Summary:

What is known on the subject?

* Remission is employed as a criteria in many studies addressing efficacy of antipsychotic medication and outcome for people with schizophrenia.

* Remission is predominantly concerned with the absence of symptoms but has newer dimensions such as 'functional remission' and 'complete remission'.

* Remission is less utilised in everyday clinical practice as the term recovery is favoured by most healthcare staff.

What this paper adds to the knowledge?

* A qualitative perspective of remission in schizophrenia.

* A consideration of stakeholder groups affected by the issue of remission in schizophrenia.

* Clarity around the phenomena of remission.

What are the implications for practice?

* The loss of clarity around remission may develop a negative impact upon the understanding of recovery

* The reduction of understanding or ambiguity may inhibit the development or use of contemporary, evidence-based approaches.

Abstract:

Introduction:

Remission is synonymous within physical disorders, but less known and utilised in relation to people with a diagnosis of schizophrenia. Following work by Andreasen *et al* (2005) the notion of remission in schizophrenia became more widely utilised as symptomatic remission and was employed as an outcome measure primarily addressing medication efficacy. The language, perception and social construction of remission for people with a diagnosis of schizophrenia is of paramount importance. To date, there has not been any published material with respect of consultation with service users regarding their personal interpretations and possible concerns around the utilisation of the concept of remission.

Aim:

This study sought the perspectives of stakeholders (practitioners, service users and carers) and their perception of remission in relation to people with a diagnosis of schizophrenia; in order to gain a fuller understanding of how remission is socially constructed for this group.

Method:

A qualitative approach employing a constructivist grounded theory (Charmaz, 2006) methodology was employed. Service users, carers and practitioners generated data via in-depth interviews. Data was subjected to *Initial, Focused, Axial* and *Theoretical* coding.

Results:

Four possible trajectories where generated from the data which could be played out within clinical practice. Also the position of remission in relation to recovery was established. Recovery remains the favoured term to address progress for service users.

Background:

Whilst remission is established for a myriad of illness' and physical disorders it is relatively new to the field of mental health. Within mental health remission was initially employed to address depression and anxiety (Kelsey, 2001; Nemeroff *et al*, 2003). Interest developed with regard to utilising the concept of remission for people with a diagnosis of schizophrenia. The Remission in Schizophrenia Working Group [RSWG] headed by Nancy Andreasen published a, somewhat influential, paper in 2005 consequentially interest escalated. Andreasen *et al* (2005) introduced criteria for remission that was utilised by many, but predominantly to address symptom reduction and efficacy of medication, within research as opposed to clinical practice. However, further research has since revealed an interest in 'functional remission' (Boden *et al,* 2009; Karow *et al,* 2012; Boyer *et al,* 2013) which addresses a broader focus than symptomatic remission and 'complete remission' which is seen as a combination of both clinical and functional remission (Kurihaha *et al*, 2011; Prikryl *et al*, 2013).

Andreasen *et al* (2005) viewed remission as part of the process or pathway to recovery; with recovery being viewed as the ultimate treatment goal. Very much like schizophrenia, recovery propagates debate regarding the lack of a consensus (Ford, 2016). Also, criticism has been rounded at 'professionals' for hijacking the term recovery and employing it as an outcome measure rather than a process as intended by the service user movement who originally developed the concept (Coleman, 1999; Deegan, 2002; and Frese *et al*, 2009). Recovery should extend beyond secondary mental health services, yet, reluctance to discharge back to primary care is apparent for people with a diagnosis of schizophrenia. The negative and adhesive nature of the diagnostic label of 'schizophrenia' contributes to this major issue. Remission as a concept may possibly have an impact upon this, but exploration is required before any certainty can be assured. Exploration beyond the efficacy of medication could determine whether remission may be useful to facilitate discharge back to primary care for some people previously diagnosed with schizophrenia.

Method:

An interpretivist approach is a method of gaining an understanding of the world as experienced and made meaningful by people (Collins, 2010). As a consequence a constructivist grounded theory (Charmaz, 2006) methodology was adopted. Participants were interviewed to generate data concerning their interpretation of remission.

Sample:

The sample was purposive in nature utilising participants from two-community mental health teams. The study was conducted in two phases, with the first phase consisting of practitioners from within these two mental health teams;

Participants for Phase One

Team 1	*Team 2*
Social Worker (F)	Social Worker (F)
Mental Health Nurse (M)	Mental Health Nurse (M)
Psychologist (F)	Psychologist (F)
Consultant Psychiatrist (F)	Consultant Psychiatrist (F)
Occupational Therapist (f)	

The variety of professional disciplines (& gender) within this sample of 9 participants can be seen above. The rationale for initially generating the data from practitioners was to balance any possible preconceptions from the researcher. The range of different professional healthcare disciplines within the sample offers breadth and not exclusively a nursing perspective. The language and perceptions generated assisted in the further modification of the interview schedule for phase two (service users and carers). Overall, this enabled a more objective positioning and less influence from the researcher during the interviews.

Participants for Phase Two

Team 1	*Team 2*
Service Users (F) x3	Service Users (F) x1
Service User (M) x1	Service User (M) x5
Carers (F) x1	Carers (F) x3
Carers (M) x3	Carers (M) x0

The approach in this study offers the participants a privileged voice (Fossey *et al*, 2002); which has been scarce from research around remission in schizophrenia previously. This voice, for all participants, was afforded through in-depth interview utilising a semi-structured format. Charmaz (2014, p85) suggests that interviews are a good fit with grounded theory approaches due to being "open-ended yet directed, shaped yet emergent and paced yet unrestricted".

Data Analysis:

All interview transcripts were analysed utilising 'qualitative codes' (themes) by defining what is seen in the data (Charmaz, 2006). During coding an interpretive understanding of the phenomenon can be gained whilst accounting for the context (Charmaz, 2008). Following a constructivist grounded theory approach the coding format suggested by Charmaz (2006) was adhered to in this study. This format by Charmaz has four stages of; 'Initial', 'Focused', 'Axial' and 'Theoretical' coding.

Initially analysis was performed on data generated in phase one, then phase two and afterwards comparisons were drawn and both phases considered in preparation of the discussion. This study demonstrated a determination to move the data on beyond the narrative stage, as this is a concern expressed by Elliott and Jordan (2010) in relation to grounded theory. Diagramming and concept mapping as advocated by Clarke (2005) was employed to overcome this. Theoretical sensitivity was also employed to demonstrate phenomena in abstract terms (Charmaz, 2014) and to illustrate the openness, transparency and intention of the study (Gibson & Hartman, 2014).

Findings and Discussion:

Both phases, coincidentally, produced 12 main themes with a variety of sub-themes (in brackets).

Phase One (practitioners):

Perspectives of Remission *(Application; Formal use; Illness/Symptom orientated; 'Making sense of'; Remission & Recovery).* ***Role. Comprehension of service users. Recovery*** *(Individual; Professional issues).* ***Stigma & media. Return of symptoms. Medicalisation. Service interface. Language & conceptualising. Process & pathway. Measurement & tools. Physical symptoms.***

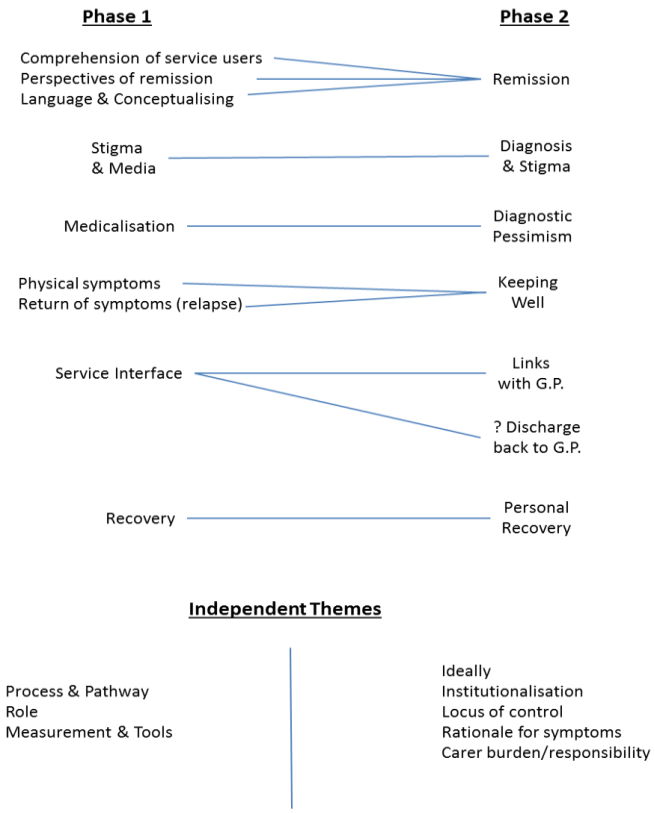
Phase Two (Service users & carers):

Remission *(Care team using the word remission; Have heard of it but vague/confusing; Have heard of it & got a conceptual rationale; In relation to mental health; In remission?).* ***Diagnosis & stigma*** *(Employment; Social stigma).* ***Carer burden/responsibility. Possibility of discharge back to GP*** *(Accepting; Resenting).* ***Ideally*** *(Social [vocational]; Status quo; Symptoms).* ***Links with GP. Institutionalisation*** *(Practitioner as a friend;*

Completeness; Discharge anxiety). ***Locus of control*** *(Healthcare team; Self or others).* ***Personal recovery.*** ***Keeping well*** *(Carer & family intervention; Medical & service intervention; Personal coping & management strategies; Social intervention).* ***Diagnostic pessimism*** *(Self; Service).* ***Rationale for symptoms.***

A mapping of the themes (Figure 1) was utilised to gain a visual interpretation and comparison.

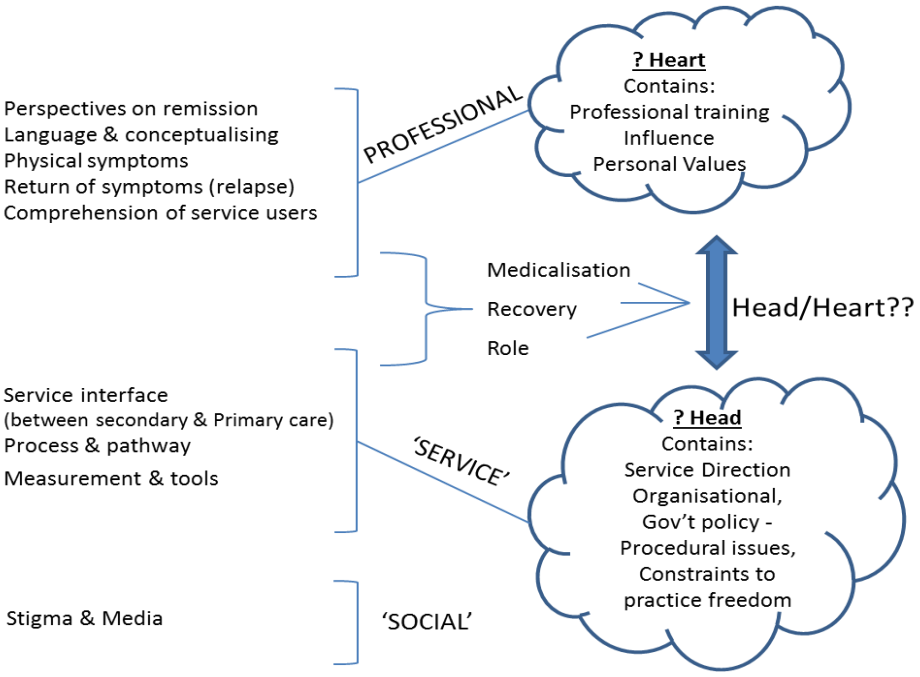
Figure 1. Comparison of themes.



Whilst similarities were apparent there were some independent themes which were specific too. The differences may be obvious and stem from the fact that one group of participants work with people in mental health service whilst the others are 'served' by these mental health services. Comparisons are drawn in relation to themes of a similar character; although the language may be different similar elements are present in these themes. Themes for practitioners that may be viewed as independent are; 'process & pathway', 'role' and 'measurement & tools'. Service users and carers may not have been exposed to these in the same way that practitioners would have been. Likewise, the independent themes from phase two ('ideally', 'Institutionalisation', 'locus of control', 'rationale for symptoms' and 'carer burden/responsibility') are more personal and carry subjective elements that practitioners may not have experienced at first-hand.

Whilst employing a method of constant comparison with the data from phase one a diagrammatic representation was developed in an attempt to attain further clarity (Figure 2).

Figure 2. Representation of 'Head and Heart'



Displaying the themes in this format allowed them to be appreciated as derivations from either 'the head' or 'the heart'. It has been suggest by Goleman (1995) that we have a rational mind that thinks and an emotional mind that feels. However, philosophers, Hegel and Dewey were opposed to dualistic and dichotomous thinking, including that between cognition and emotion despite this characterising the mainstream of ethical theory beforehand (Miller *et al,* 1996). Upon reflection, it is perhaps a more colloquial expression or discourse within healthcare to refer to the aspects of the head and the heart. This may be consequential as little of our lives are governed by logic alone, generally, as our emotional world motivates our decisions and actions (Freshwater and Stickley, 2004). Baker (2013) associates the head with 'knowledge' and 'science' whereas; the heart is associated to 'feelings' and the 'art'. The same can be appreciated in this figure as; the themes allied to the head are derived from service direction, organisational perspectives including government policy and procedures, and constraints to practice freedom. When employing the term 'practice freedom' it is in the context of the practitioner utilising autonomy and having authority to be creative and flexible in their delivery of interventions and approaches with service users and carers, as opposed to being stifled and contained by the procedural restraints imposed by the organisation or team. This can then be akin to Bakers' (2013) concept of knowledge and science as practitioners may be driven more from the head in a cognitive manner. The themes allied to the 'heart' are derived from professional training, influence of colleagues & peers, and personal values and could be aligned to 'feelings' or 'art'. One cannot describe the art and science of nursing without reference to emotions (Freshwater & Stickley, 2004). Whilst only a small number of the

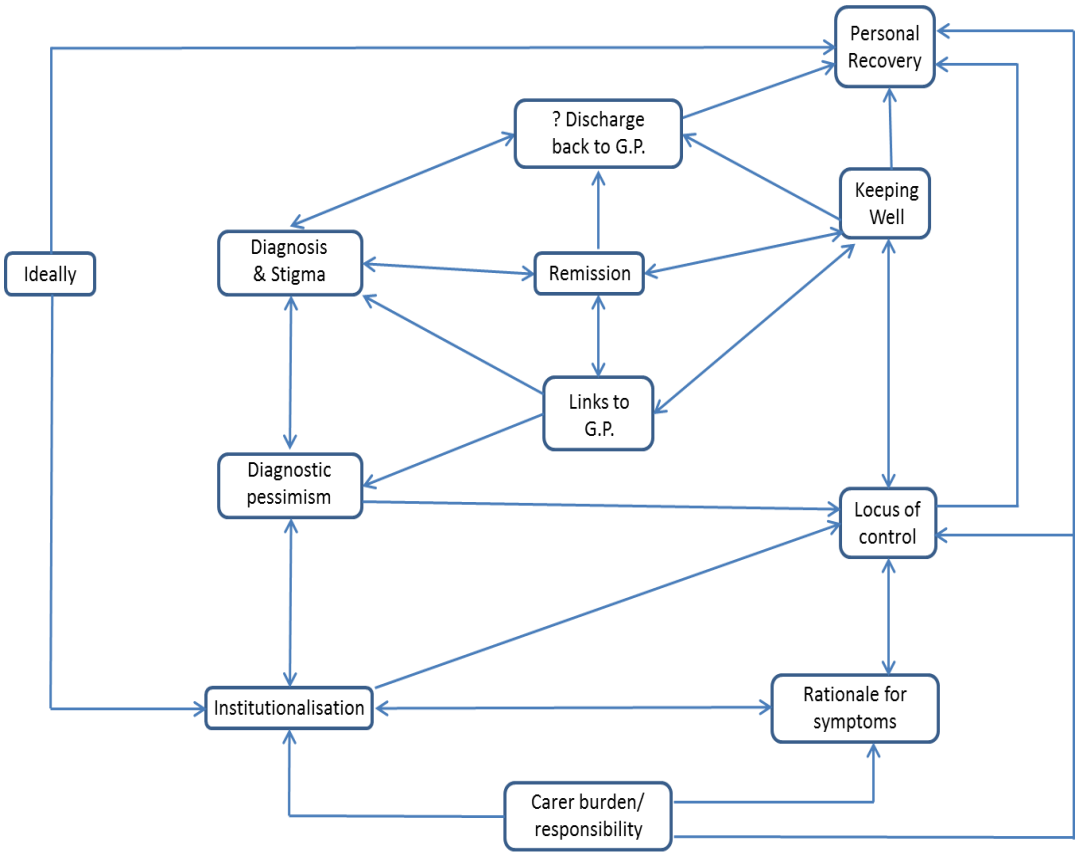
participants in this study are nurses this would be applicable across all areas of healthcare. Weber (1922, *cited in* Poggi, 2005) described three forms of social action and this may share some resemblance with the head/heart representation;

- Traditional Action (motivated by customs and tradition) =? Head
- Effective Action (motivated by emotions and impulses) =? Heart
- Purposive-Rational Action (motivated by conscious methodical calculation of available means of achieving desired ends) =? Combination of Head & Heart

Weber's hermeneutic tendency allowed him to postulate that in order to survive human beings strive to make sense of the world, this is achieved by attaching meaning to the innumerable, contradictory aspects which realty presents (Poggi, 2005). Baker (2013) suggests that when we attend to our own head and heart we then have increased ability to care effectively for our patient's head and heart, and they should be treated as both and 'not either or', again perhaps rejecting the dualistic approach.

The analysis of the themes continued to produce connections and interconnections. Codes become more elaborate through the use of diagramming and cartographic representation (Charmaz, 2014). The themes generated from service users and carers became more malleable and it was these themes which generated a conceptual map (Figure 3).

Figure 3. Conceptual Map of All Themes from Phase Two



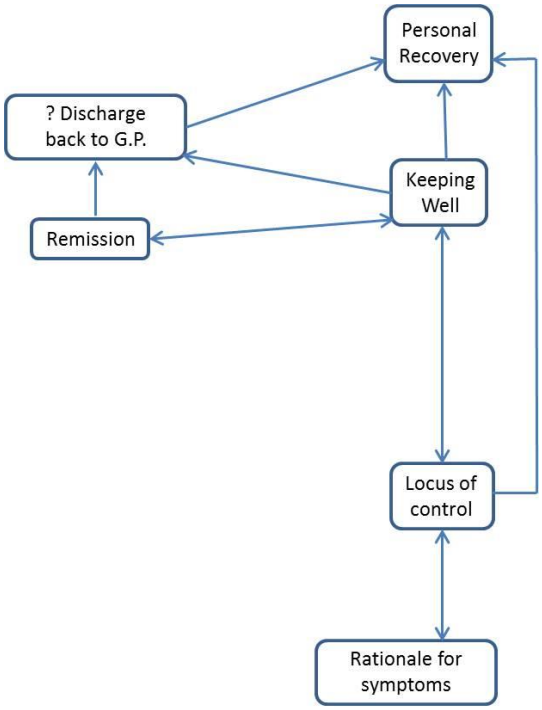
This cartographic representation of the themes from service users and carers is symbolic of the relationship of the themes and the manner in which service users may navigate through mental health services. Concern about possible relapse and the diverse range of symptoms experienced contribute to the conundrum of how best people may steer through services. Care pathways have been devised, applied and revised and despite assertion by Tsang (2012, p39) that "Mental health services have been leading the way in using a pathway-based approach as a means of achieving a move away from hospital-based care". This has had little impact upon people gaining discharge back to primary care.

This conceptual map of themes was further analysed resulting in the generation of four possible trajectories which service users 'may take' or end up following. These four trajectories are routes embedded within the conceptual map of the themes, each will be presented:

Possible Trajectory 1 – 'Collaborative Approach'

The concept of collaboration as a beneficial approach within mental health services has been well documented (Keen & Lakeman, 2009; Baldwin, 2012). As Mills (2000) infers there is a role to play for both

the service user and the practitioner in the development of coping methods and new understandings around psychosis. This can be a beneficial alliance as Lipczynska (2011) asserts that effective collaboration and communication with service users may possibly improve diagnosis, treatment and recovery. This trajectory would demonstrate a positive collaborative approach that would fully utilise the concept of remission for a person with schizophrenia. Remission would be a shared concept that would be discussed by practitioners in secondary mental health services with the service user from an early point and worked towards as part of the personal journey to recovery. Of the four possible trajectories this would be the most desirable, in that it would ultimately facilitate discharge and allow the service user to take the next steps beyond mental health service input on the journey to 'full' or 'personal' recovery.



'Rationale for symptoms' – Ideally the service user develops a positive approach to their symptoms which is supported by the practitioners and healthcare team involved too. It is not just the disorder itself which determines the long-term course and outcome of schizophrenia, but the relationship or interaction between the person and the disorder (Hoffmann *et al*, 2000). It can be surmised that if this interaction (between the person and the disorder) is positive then the outcome can be too. Consequentially this would be a good starting point when adopting a recovery focused approach. If practitioners can adopt and work with a psychological approach to arising issues this may prove beneficial. As offering explanations and working collaboratively with service users in a manner that may 'normalise' symptoms they experience rather than catastrophising them may reduce distress and increase understanding (Nelson, 1997; Turkington *et al,* 2009). Destigmatising and normalising the

symptoms adopts a cognitive, behavioural approach which Nelson (1997) advocates practitioners should adopt.

'Locus of control' – Warner *et al* (1989) stipulate that it is both a combination of accepting a diagnosis of mental illness and adopting an internal locus of control that is associated with improved outcomes in psychosis. Therefore, if this trajectory is to be realised then the locus of control has to be acknowledged by the service user. Also, importantly, there has to be no objection or resistance to this from practitioners who may be tempted to assume that they 'know best'.

'Keeping well' – The ideal scenario would be that the service user understands what is keeping them well and therefore able to demonstrate factors of resilience to protect against relapse. It is understandable that people who have had psychotic experiences do have concerns about becoming unwell again (Gumley *et al,* 1999). If the mental health team manage this well, in a collaborative approach, and enable service users to understand difficulties, know what the treatment options are and ultimately make better choices as suggested by Turkington *et al* (2009) then they need not be in constant fear of relapse. Again this adds to the overall feeling for service users that they are establishing some control over their life again.

'Remission' – If a person has managed to 'keep well' for a period of six months, according to the criteria by Andreasen *et al* (2005), then they should be deemed to be in remission. There may be value in utilising the concept of remission at this stage. The rationale for stating this is due to the possibility of 'remission' being utilised as a conduit or potential route to primary care for a person deemed well enough. Ideally, a service user would identify an improvement over a period of time accompanied by a reduction in symptoms. This improvement would also be assessed and acknowledged by the care team and consequentially the GP and primary care team would be accepting to receive the person into primary are.

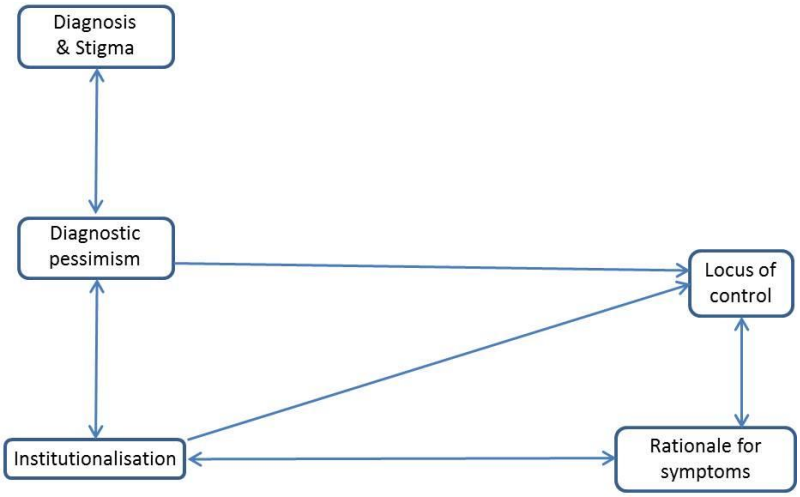
'? Discharge back to GP' – Given that the person has evidence of being in remission then the primary care team as a whole should be accepting. It has to be appreciated that this would be facilitated with sensitivity for all stakeholders and to assist the person to embrace this further step in their quest for recovery. The GP and primary care team would be made fully aware of the plan including contingency planning and offered advice and a quick route back if required.

'Personal Recovery' – The service user is fully integrated into, and accepted into society. Thus the person can go on to regain a sense of citizenship (Sayce, 2000) which would also be enhanced by being free of

the diagnosis previously attached. Remission would signify that people would be; "…below the threshold typically utilized in justifying an initial diagnosis of schizophrenia" (Andreasen *et al,* 2005, p442).

Possible Trajectory 2 – 'Self-Fulfilling Prophecy'

This possible trajectory would not, in terms of recovery, be considered ideal. There would be the attempt at collaborative working from practitioners but this may be refused or rebuffed by the service user as they feel that they are unwell or could not attempt, the perceived, big steps towards recovery. If we accept that the diagnosis of schizophrenia is a classical notion of madness with issues of power lying at its heart (Coles, 2013), then it becomes comprehensible that the person receiving this diagnosis may develop undesirable feelings such as being powerless or hopeless. Marks *et al* (2011) highlight that one of the sources of self-efficacy is 'vicarious experiences'. As a consequence service users witnessing other people in a similar situation may dwell on the fact that they do not observe people achieve recovery quickly, thus developing the vicarious experience to trigger self-doubt.



'Institutionalisation' – Despite receiving input from community-based services, service users of both teams (within this study) alluded to issues that were under the theme of institutionalisation. The sub-themes of 'practitioner as a friend', 'completeness' and 'discharge anxiety' were the areas highlighted that may impact negatively with regard to recovery. Without the 'world' of secondary mental health services some service users may have concerns and anxieties of feeling lost, abandoned or neglected. Whilst it would be a role for practitioners to facilitate empowerment and hope assisting people to overcome this (Schrank & Slade, 2007), the feeling may be too omnipotent for some people.

'Diagnostic pessimism' – As the theme describes there can be pessimism associated with receiving and carrying a diagnosis of schizophrenia. In this possible trajectory the pessimism reinforces the sick role that people may adopt as described by Johnstone (2008, p13) "The common cultural understanding of being

diagnosed as ill ('schizophrenic' or 'psychotic' etc.) is that you are not responsible for your condition and need to rely on expert help".

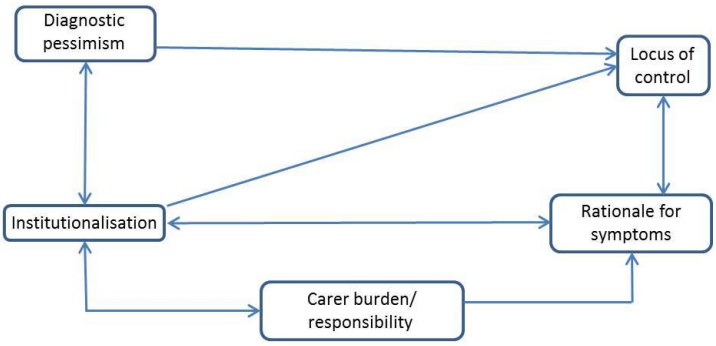
'Diagnosis & Stigma' – A respondent in a study by Thomas *et al* (2013, p136) reported, "The humiliation of being labelled schizophrenic threatened to become a self-fulfilling prophecy". Thornicroft (2006, p156) states, "…Those who expect discrimination are more likely to accept it when it does occur: a self-fulfilling cycle". A wide range of impacts were described for people since gaining the diagnosis of schizophrenia and this included experiencing stigma, because of the way people now saw them since the label was applied (Thomas *et al*, 2013). Ultimately receiving a diagnosis of schizophrenia often compounds further the issues caused by the symptomatology and this can generate a negative view that recovery is unlikely.

'Locus of control' – The importance of adopting a feeling of control has previously been mentioned. By contrast, a self-perpetuating downward cycle can result from an untreated negative approach or outlook resulting in a more external locus of control (Harrow *et al*, 2009). Hopelessness is also highlighted as a factor that may contribute to chronicity (Hoffmann *et al,* 2000). People with a diagnosis of schizophrenia may abandon responsibility and/or hope if feelings are that things are beyond them.

'Rationale for symptoms' – As opposed to understanding and having some sense of control over symptoms, service users in this possible trajectory may be inclined to accept the symptoms as a consequence of the fact they have schizophrenia. Barham & Hayward (1998, p167) explain that if a persons' grasp is that they have "some kind of chemical reaction in the brain", this will place it in the domain of illness, as an 'I have' experience. Consequentially, people also become the thing they are labelled (Estroff, 1989). This experience, therefore, is seen to necessitate medical intervention and does not lend itself so well to methods of self-help. This may in turn affect the relationship between practitioners and service users.

Possible Trajectory 3 – 'Pessimistic Outlook'

This possible trajectory is somewhat similar to the 'self-fulfilling prophecy' in that it is not the ideal scenario for a recovery focused approach. Whereby the emphasis for the previous trajectory may have been predominantly generated from the thoughts and feelings of service users, this is more to do with negativity from practitioners and services, along with the influence from carers and family. Whilst this may not be vindictive or actually intended it nevertheless has the capability to arrest any movement towards recovery.



'Diagnostic pessimism' – Within this possible trajectory, service users may encounter practitioners who remain very traditional in their views and approaches for people with a diagnosis of schizophrenia. Practitioners adhering to measures of symptomatology as their only means to assess and work with service users may be demonstrating a restrictive and blinkered approach.

'Locus of control' – Rather than the service user feeling helpless and not able to adopt the locus of control (as in trajectory 2, above), in this possible trajectory the practitioner may automatically assume control. This cuts across the grain of the sentiment asserted by Shepherd *et al* (2008) when they state that in order to facilitate independence the practitioners are there to be 'on tap, not on top!' Johnstone (2013) highlights a common source of irritation for clinical staff is the perceived passivity of the patients in relation to the sick role. If this is the overriding feeling for staff then they may feel it is better to 'do it for them' rather than allowing the service user to assume responsibility. It is a powerful position that mental health service providers occupy in relation to service user's hope (Hobbs & Baker, 2012), and giving the impression that practitioners hold the locus of control will serve to diminish any hope that the service user was developing.

'Rationale for symptoms' – Irrespective of what the service user has gleamed as a rationale for their symptoms, if the practitioner emphasises that these are as a consequence of a medical or biological causation this perhaps indicates that medication may be the only answer. The threat of losing hope may provoke many representations that would not be conducive to a therapeutic relationship. Also when distress gets treated as a medical illness, the personal meanings of people's experiences are downplayed (Johnstone, 2013). Overall this is a pessimistic view of therapeutic opportunities.

'Institutionalisation' – Despite service users wishing to recover and work towards potential discharge the emphasis by the healthcare team in this possible trajectory is one of maintenance. This may be fuelled by the nihilistic view of the diagnosis and possibly the culture of the team resulting in a risk averse manner

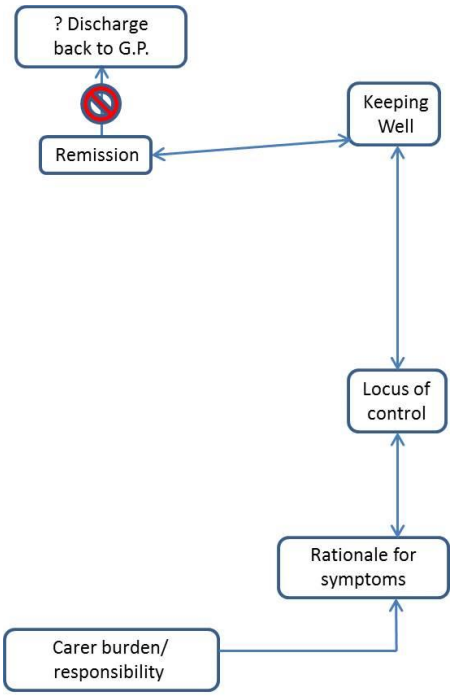
that maintains the service user within services. If mental health services are to over systematise recovery and risk losing sight of the individual person Deegan (1996) asserts than you have got it wrong.

'Carer burden/responsibility' – The profound effects of mental health problems can impact upon family, friends and carers too (Repper, 2012). One particular difficulty that Repper (2012), highlights is the difficulty in navigating an array of different services and professionals who may not recognise or understand the concerns. These compounding issues may make the carers feel burdened and in need of support and assistance, therefore the prospect of the person they care for being discharged may induce fear and increased anxiety.

This possible trajectory may have a service user that is keen to progress and make attempts to recover their life, but they would be stifled by mental health services, practitioners and their carers'.

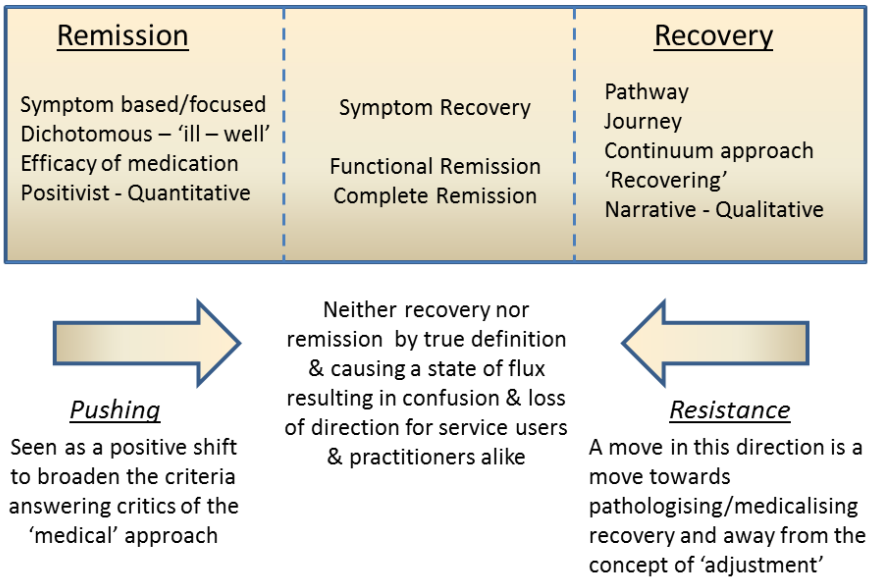
Possible Trajectory 4 – 'Inhibitive; Glass Ceiling'

This possible trajectory resembles the 'collaborative approach' trajectory. However, the difference being that, despite good progress being made within secondary mental health services, discharge back to the primary care team and GP is thwarted. Figure 19 below demonstrates the point where this impasse may occur, between 'remission' and '? Discharge back to GP'.



The data generated from the participants highlight the difficulties encountered when the point of discharge is achieved for people who had been given a diagnosis of schizophrenia, despite being deemed well enough at that point. If practitioners are utilising the 'Remission criteria' as presented by Andreasen *et al,* (2005); then the person would be deemed to have symptoms below the threshold for a diagnosis of schizophrenia. Hopefully, this would reduce some of the initial concerns of the primary care team. Despite this concern is, usually, due to the fact that the person is still requiring some form of antipsychotic medication. If the route by which this antipsychotic medication is to be administered is via intramuscular injection then the issues affecting discharge becomes much greater. This may appear to be a simplistic view, based purely on medication, and there may be much more embedded in the issues that concern staff in primary care; cost of physical healthcare, possibly 'payment by results', and overall monitoring. However, medication is the most common reason offered in terms of refusal of access back to primary care and the principle reason why this possible trajectory would be inhibitive. Some people may doubt whether people with a diagnosis of schizophrenia can recover; in fact one of the psychiatrists interviewed for this study stated that, if a person had recovered they would doubt the accuracy of the initial diagnosis. The issue is that the service user remains involved within mental health services and as a consequence 'full' or 'personal' recovery is compromised or at best limited. This would certainly not be in keeping with the rhetoric from mental health services who hopefully appreciate that, "Stagnation in mental health services can severely jeopardise an individual's recovery process" (Ford, 2010, p23). In addition to all of the components already mentioned, this possible trajectory would have the service user gaining full support, not in a dependent manner, by carers and family in their potential venture back to primary care and ultimately recovery.

This possible trajectory may have a service user that is keen to progress and make attempts to recover their life, supportive carers and the backing of the secondary mental health team. The problem is clearly in the transition and acceptance back to primary care from the team who would be receiving this person.



Overall, remission was initially utilised as a symptom outcome measure which, for some, has developed to signify and incorporate more than its original notion. Borrowed from physical disorders and after use with depression it was used for people with schizophrenia. With others adding broader contexts such as 'functional' remission and 'complete' remission this has served to further confuse issues relating to recovery. Practitioners, service users and carers are not familiar with remission in the context of schizophrenia, some appreciate it may be useful whilst others feel it reverts back to a purist medical approach. For service users and carers there is some confusion what it is and might signify.

Therefore the social construction of remission, in respect of people with schizophrenia, may be regarded as;

A concept imposed by a group of people that can utilise it, trying to convince others to adopt it on the merits of their research; but without the full consultation of all involved.

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